


Intimacy for older adults in long-term care: a need, a right, a privilege—or a kind of care?

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ABSTRACT

Background To investigate attitudes of staff, residents and family members in long-term care towards sex and intimacy among older adults, specifically the extent to which they conceptualise sex and intimacy as a need, a right, a privilege or as a component of overall well-being.

Methods The present study was a part of a two-arm mixed-methods cross-sectional study using a concurrent triangulation design. A validated survey tool was developed; 433 staff surveys were collected from 35 facilities across the country. Interviews were conducted with 75 staff, residents and family members.

Results It was common for staff, residents and family members to talk about intimacy and sexuality in terms of rights and needs. As well as using the language of needs and rights, it was common for participants to use terms related to well-being, such as fun, happiness or being miserable. One participant in particular (a staff member) described receiving intimate touch as a 'kind of care'—a particularly useful way of framing the conversation.

Conclusion While staff, residents and family frequently used the familiar language of needs and rights to discuss access to intimate touch, they also used the language of well-being and care. Reframing the conversation in this way serves a useful purpose: it shifts the focus from simply meeting minimum obligations to a salutogenic approach—one that focuses on caring for the whole person in order to improve overall well-being and quality of life.

INTRODUCTION

A debate has been framed to take a position on whether intimacy and sexuality for older adults in particular in long-term care is a need or a right,^{1–3} and whether it is part of the responsibility of a long-term care facility to attend to the intimacy and sexuality of older adult residents,^{4,5} particularly for gender and sexually diverse residents.^{6,7} Notions of human rights and sexual citizenship have been introduced into the discourse.^{8–11} Expanding the discourse in this way opens up new space for how intimacy and sexuality are conceptualised for older adults in long-term care. This has practical implications, because the different conceptions imply different sets of attitudes and obligations on the part of the facility.

If intimacy and sexuality are conceptualised as needs, care providers have an obligation to ensure these needs are met (in the same way they have an obligation to ensure other needs like nutrition and medical care are met). If intimacy and sexuality are conceptualised as rights, then care providers must ensure that they are not impinging on residents' abilities to exercise that right. If intimacy and

sexuality are treated as a privilege, care providers have no obligations to ensure residents can act on their desires in this domain.

The problem with all three of these approaches is that the question becomes one of the care facility merely meeting their minimum obligations to the residents and managing the associated risks. We believe the needs, rights or privilege debate distracts from a resident-focused approach which places well-being at the centre of care. In the traditional framing of these debates, sexuality and intimacy are problematised, rather than perceived as an integral part of an individual's life, giving them meaning and purpose. Furthermore, staff in particular (who navigate these questions as part of their everyday working life) are well aware of the importance of well-being-related considerations in the context of intimacy and sexuality, such as happiness (and conversely, misery), and that they contribute to overall quality of life.^{12–14}

A salutogenic approach contextualises relationship, intimacy and sexuality as part of an overall person-centred approach which focuses on well-being, strengths, resilience and quality of life of an individual. In particular, Greene and Cohen's resilience-enhancing framework shifts the focus of care away from risk management interventions toward interventions that build (and build on) the existing capacities of older adult residents in long-term care, and promote resident well-being.¹⁵ Such an approach fits well with an overall approach that places the person at the centre of care, with the aim of providing care which responds to the needs, preferences and values of residents.¹⁶ In other words, we propose that the needs and rights debate both distract from what we propose should be the primary purpose of long-term care facilities which focus on older adults: supporting an individual to thrive, or as one of our participants put it, living their lives until they do not. Evidence from our staff participants shows that those working in the sector are already taking these considerations into account in their decision-making—theory (and policy) on this issue should take their insights into account.

METHODS

Design

These data are drawn from a national two-arm mixed-methods cross-sectional study. A social constructionist approach was used to obtain and analyse the qualitative data. Such an approach focuses on how meanings are created, sustained, negotiated and interrupted.¹⁷



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Procedure and participants

The first arm of the study was an anonymous, self-administered survey completed by 433 staff (response rate estimated at 62.5%). The first arm of the study included a staff-only survey consisting of 20 questions on knowledge, attitude and behaviours related to sexuality and ageing, with a 5-point Likert scale of responses ranging from strongly agree to strongly disagree; some items were reverse scored. Composite median scores were identified by multiplying the mean score (3) by the number of possible responses. Composite knowledge scores ranged from 5 to 35, median $(7 \times 3) = 21$; with higher scores representing a higher level of knowledge and lower scores representing a lower level of knowledge. Composite attitude scores ranged from 10 to 50, median $(10 \times 3) = 30$; with higher scores representing positive attitude and lower scores representing negative attitude. Composite behaviour scores ranged from 3 to 15, median $(3 \times 3) = 9$; with higher scores representing positive behaviour and lower scores representing negative behaviour. The internal reliability assessed by Cronbach's alpha for the entire survey was 0.81, which we assessed as a satisfactory level of internal reliability.

The second arm was semistructured interviews with staff, residents and family members conducted between October 2018 and October 2019 (all interviews were completed before COVID-19). Participants recruited from a non-probability sample of 35 long-term care facilities, stratified by region and size of the facility. Staff, residents and family members were then invited to contact research team members if they were willing to be interviewed. Project staff conducted 61 interviews with 77 participants. All interviews took place at a time convenient for participants and in a safe and quiet venue in the facility that provided privacy and relative comfort. Interviews were completed as follows: staff, 19 individual interviews, and four groups with a total of 17 additional people; residents, 26 interviews with 28 people; family members, 12 interviews with 13 people. Interview length depended on participant engagement and fatigue; the shortest was 20 min, and the longest several hours over 2 days. In this report, quotations from participants are identified by an initial letter indicated staff (S), resident (R) or family member (F) and a participant's number. The gender of the participants completes the quotation identification (eg, S1F is a staff interview, and this participant was female; staff group members were all female). For cultural reasons, some staff preferred to be interviewed in pairs or groups; this is not unusual in research in Aotearoa New Zealand, particularly among participants from Pacific Island nations.

▶ A demographic profile of staff and resident interview participants is found in online supplemental tables 2 and 3.

Ethical considerations

The ethics committee was satisfied that the research team had demonstrated expertise in sexuality research with marginalised people. Participation in the study was voluntary. Participants were informed about the objectives of the study and written consent was obtained before interviews. The interviews were conducted by researchers who were trained and experienced health and social care providers with experience in sexuality research who were capable of managing potential discomfort. Regarding involvement of residents with cognitive impairment, we used the approach described by Brannelly¹⁸ to ensure that notions of protection did not exclude people unnecessarily. Where necessary, staff were consulted to confirm the competence of residents to provide consent. Proxy consent was not sought (there were no cases in which this was considered necessary).

Qualitative data analysis

Audio-recorded interviews were transcribed. Thematic analysis, guided by Braun and Clarke's¹⁹ six steps of data analysis, was undertaken to identify key themes. This process involves identification, generating initial codes, and searching for themes, reviewing themes and defining and naming themes.

Rigour

To facilitate credibility, purposive sampling of participants was used with a view to diverse characteristics of staff, residents and family members. Transcriptions were reviewed by all researchers in this study for accuracy. As part of triangulation, all five researchers reviewed transcripts separately²⁰ before proposing themes; themes were repeatedly reviewed throughout the coding process.

Quantitative data analysis

The data collected from the surveys were coded and entered into the SPSS, V.21.0²¹ for analysis. Data distribution was checked for normality; the Kolmogorov-Smirnov statistic for each variable indicated that all variables had a significance value of $p \geq 0.05$, indicating a normal distribution. Descriptive statistics were used to describe the basic features of the data in this study. We achieved our goal of recruiting participating sites nationally proportionate to the size of the facility. Age groups were roughly equally represented in the survey respondents, with the greatest number ($n=97$, 25.1%) being recorded in the age group 51–60 years old. Slightly more than half ($n=217$, 55.9%) of respondents identified their role as healthcare assistant, which is an entry level role requiring minimal formal education; 35 (9.0%) were managers, 66 (17.0%) were nurses and 70 (18.1%) identified their roles as something else (social worker, occupational therapist, diversional (recreational) therapist, etc). Online supplemental table 1 summarises the demographic characteristics of staff survey respondents.

RESULTS AND DISCUSSION

The full results of the quantitative survey are available in the full report of the study 'What Counts as Consent? Sexuality and Ethical Deliberation in Residential Aged Care'.²²

The results relevant to staff perceptions of the status of sexual intimacy as a right and the role a facility should play in helping (or not helping) residents to exercise those rights are as follows. From the quantitative survey, we know that a significant number of staff in long-term care facilities think of at least some aspects of sexual intimacy as having the status of a right. For example, 281 (64.9%) of participants agreed that 'intimate relationships which involve pleasurable touch are a lifelong human right'. Only a little more than half of participants (56.6%, $n=245$) agreed that same-sex couples have the right to be sexually intimate with each other—58 participants (13.4%) disagreed with this statement, and 130 (30.0%) were neutral.

In terms of the facility ensuring residents can exercise their rights in this domain, the results were less empathic. Close to half of the participants agreed that facilities should provide a private space to allow sexual activity (49.9%, $n=216$). Participants were fairly evenly split on whether facilities should meet the needs of residents who want to use shared internet in private: 148 (34.2%) agreed, 133 (30.7%) disagreed, and 152 (35.1%) were neutral or missing. Participants were also fairly evenly divided on the question of whether facilities should provide access to sex workers: 131 (30.2%) agreed, 157 (36.3%) disagreed, and 145 (33.5%) were neutral or missing.

Whether sex work should be understood as an unacceptable form of exploitation or simply a useful means for those who are otherwise unable to engage in sexual intimacy to exercise their rights to sexual citizenship is controversial (Teela Sanders provides a useful overview of the controversies around commercial sex and disability in 'The politics of sexual citizenship: commercial sex and disability'²³). However, it is worth noting that Aotearoa New Zealand decriminalised and regulated most sex work in 2003.^{24,25} (It remains illegal to coerce someone into sex work, for a third party to facilitate sex work by someone under the age of 18 years, or to engage in sex work on a temporary visa (such as a visitor or student visa)). So in the context of this study, when participants are asked about access to sex workers they are being asked about access to an entirely legal and regulated activity.

It is clear from the qualitative data that in general, participants think sexual intimacy has the status of a right, although some people constructed it as a need. A number of staff, residents and family members expressed views which recognised the need for intimacy, the right to intimacy and the role of the long-term care facility to at least not actively prevent residents from engaging in sexual intimacy. While it was common for participants to use the language of needs and rights, many of them appealed to well-being considerations to justify treating intimacy as a right or need.

Staff

A number of staff recognised that residents had sexual and intimate needs, and linked these to considerations to do with well-being. For example, one staff member considered women's sexual needs in the context of providing aids if necessary:

Q: And, if a person came and said, "I've run out batteries for my vibrator". You would help them get new ones, and things like that?
A: Yes, that's fine. We can't deprive them for that, because that's what they need; if that's what makes them feel better. Yeah, we just leave [them to it]. (S2Group)

In general, staff also recognised that residents had a right to sexual intimacy: "I don't see any problem, [with residents] intimate relationship with other people, because it's their right. If that will benefit them, and make them better and happy, then I don't see any problem with it" (S2Group).

This was true even in cases where staff members were themselves personally uncomfortable:

Q: Again, you've spoken to this already; what are your thoughts about residents being able to access sex workers or escorts?
A: Personally, I don't feel that comfortable with it myself, but it's their right and so we are here to make sure that they are supported, happy and they have their rights. (S24F)

Staff also recognised the need for education on these issues, and found policies addressing them useful.

Q: Do you think somebody at the facility would assist them, like making the call, making a safe space available for them to see a sex worker?
A: Yeah, they would do. Totally education though, because some people they might think that kind of thing you're not allowed to do that. But, through education, through training, they would get to understand their needs as well. (S19M)

One manager described how education was used in her facility to help staff manage situations they may be uncomfortable with:

I teach all of the staff intimacy in the elderly. So, everybody is aware that if they go into a room and a gentleman is masturbating, they just quietly back out, close the door and go back in half an hour. That's his right and so you don't get shocked or, "Oh, he did such and such", you just walk away. A lot of these people have had a normal sex life; their partner dies and it's [sexual expression is] cut off, but that doesn't take away the urges, the feelings, or the need. It's not offensive, and it's not dirty; it's just natural and normal. (S23F)

Another manager had an interesting perspective on the sexual and intimate needs of residents, describing meeting these needs as a kind of care, akin to other intimate cares performed by staff:

Q: What about when you have a gentleman or a woman for that matter, who has a sexual need that can't be met within the facility; have you come across that?
A: We did have one in this other facility I was working in, and we actually paid for him... it was a male; he paid but we arranged for him to have a female visitor, and again 'Do not disturb sign'; same thing. It doesn't say why you don't want to be disturbed, it could be that you're having a sleep or whatever. Everyone had them, so you weren't unusual. You didn't draw attention to the fact.

Q: So, all doors have those on?

A: Every door had a 'Do not disturb' sign, and some of them had, 'Care in progress' so what it intimated was that you were being washed or showered in your room, so please do not enter, so that was even more discrete. Because it was kind of a care that was in progress. (S22F)

Residents

While both quantitative and the qualitative results suggest that the majority of staff recognise sexuality as a right, and that a significant number of staff believe that the facility should and would support residents to exercise those rights, including taking such measures as respecting privacy when necessary and arranging the services of sex workers when requested, residents expressed some frustration, and reported not feeling supported in getting their needs met.

Male and female residents both expressed a desire or need for intimate touch. One male resident, when asked if he would like a sexual relationship, responded: "Would I like a sexual relationship? I'm not sure I'm capable of the same sort of sexual relationship I used to have then, now. I'm 86 now; I'm past it more or less but it doesn't stop me thinking about it" (R10M).

Another male resident put it this way:

Being a male, I like to be touched occasionally. I mean, I do have help in the shower, but nothing sexual. There's absolutely nothing sexual at all. And, that's a wee bit hard to take, because I'm still trying to regain who I am sexually. It's not some person who I don't want to touch me touch me; in other words, I'm making the choice of who is touching me, rather than not having had that choice. (R8M)

When asked if he was able to make that choice, he responded by framing desire as a need that staff were uncomfortable helping residents to meet:

Yes, but it's costing a lot of money. In that regard, I don't really know what the answer is. Men's needs and women's needs are different. It's not something that I think they're very comfortable with, the staff, talking about it. (R8M)

What these quotes highlight is that having sexual and intimate needs met is often effectively a privilege for those with money, rather than a right which any resident can exercise. It was common for those who wished to engage in sexual intimacy to experience frustration—access to sexual intimacy felt to them like a privilege they had lost when they lost access to the greater privacy living at home afforded them.

However, when residents were able to enjoy sexual intimacy, their overall well-being was greatly improved. One female resident described her feelings toward intimacy, emphasising how much ‘fun’ a new relationship was:

It's rather fun and you have to have a laugh. It's wonderful and was the last thing I expected. I was so glad when all that ‘stuff’ had finished. I knew [name] liked me, he is 93, I said to my friend in the resthome do you think he would want sex and she grinned at me. I got into it fairly quickly, it didn't take long to remember. [Name] went to the doctor to get some pills to help him. (R15F)

Family

Some family members expressed similar attitudes to the staff we interviewed. The family members also recognised the need their relative in care had for intimate touch, and the effect that lack of access to intimate touch has on the well-being of residents, but the family members tended to experience this as something awkward:

There were people who were very tactile with us; physical touch was something they were obviously really craving. They would always want to come and give the kids a hug and the kids would be a little bit awkward about that sometimes because they didn't know this person. (F5F)

One family member in particular was supportive of the idea that sexual intimacy was a need that the long-term care facility should have a role in facilitating.

It could be encouraged, like posters around, ‘Don't be afraid to ask if your partner wants to come and have lunch with you and you feel a little bit... and you want to become intimate.’ (F10F)

It is interesting to note that compared with the views of staff, who saw their role as something closer to allowing (giving privacy when required) or discreetly facilitating (arranging for a discreet visit from a sex worker, or providing batteries for vibrators if required), this family member saw the role of the facility as being one of openly and publicly encouraging intimacy.

However, not all family members were as open to the idea of intimacy in the context of a long-term care facility. There were family members who were very much against the idea of their loved one engaging in sexual intimacy in this context. But even then, it was common for the family member to recognise that rights were important here, although they expected to have their say:

Q: If you knew that there were people in the care home that were—for instance, not everybody allows sex workers into the care home, but they might facilitate people being put in a taxi and visiting, how would you feel about that?

A: Like I say, if it was my mum, no way. But other people have their own rights. If their family is okay with it, then sure. (F8F)

Another family member said about a new relationship her father had formed in the context of a long-term care facility:

“Yeah, and he needs that; everybody wants to be hugged. Everyone wants to feel loved, so why would I deny that? I do it every time I leave him. It's no different” (F7F). The same family member had had a good experience with the way the facility treated her father's relationship, but believed that this kind of positive attitude was unusual in long-term care facilities (as with residents, this contrasted with the views of the staff we interviewed who expressed the view that in general staff would be supportive even if they themselves felt uncomfortable):

This is the only health group that has that they are actually individual people and they have individual rights, and they have individual needs. A lot of the rest homes try and blanket them all as they are just residents and they just have to do as they're told, because our plan is this. I think that's why there's so many miserable people in them to be fair; I really do. (F7F)

The response from this family member encapsulates the heart of the issue: thinking about sexual intimacy in terms of rights and needs can be useful, because it can spur facilities to consider how best to help residents exercise these rights and have their needs met. But most importantly, failing to do so has a big impact on the overall well-being of residents.

CONCLUSION

Staff, residents and family frequently used the familiar language of needs and rights to discuss access to intimate touch. It is not surprising that rights in particular were frequently appealed to. An analysis of eight long-term care home policies from Anglo-phone nations found that the policy documents were heavily focused on liberal values such as autonomy, self-determination and rights. Needs were also commonly referred to, but well-being terms such as pleasure were used less frequently.²⁶

However, our participants did use the language of well-being, as well as the language of care, frequently in the context of justifying why they considered intimacy and sexuality to be a right or a need. Reframing the conversation in this way to include well-being serves a useful purpose: it shifts the focus from simply meeting minimum obligations to focusing on caring for the whole person, and considering their overall well-being and quality of life.

Therefore, we propose that rather than relying on the language of rights or needs, discussions about intimacy and sexuality for older adults in long-term care should take a salutogenic approach, as proposed by Greene and Cohen.¹⁵ Such an approach aligns with person-centred care¹⁶ which mirrors the approach that many of our staff participants appear to be taking. Further, this approach fits better in work place and home space that is made up of overlapping relationships of care (between staff, residents and family members).

In terms of policy, what we propose is that staff training materials encourage staff to focus on overall resident well-being—such materials should highlight that for many older adults in long-term care, sexual and intimate touch is still desired, important and beneficial. Focusing on well-being does not mean that staff should not also take care to minimise risks to residents where appropriate, particularly when the residents in question have a cognitive impairment. But focusing *only* on risk and ignoring the positive contribution intimacy and relationships have on the well-being of residents is not the right approach. Staff education then should therefore shift from its emphasis on compliance and risk management, and instead focus on providing guidance on applying salutogenic and person-centred

care in practice. Staff members are after all carers, and as one of our participants pointed out, this kind of touch is after all a 'kind of care'—as essential to the well-being of residents as being able to socialise or experience simple tactile pleasures such as hair cut or a massage.

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